

MARCH - APRIL 2009

# Imprint

Official publication of the Spinal Injuries Association

## New minister, new era

Now that the metaphorical ash from the political volcano that was the 2009 Queensland state election has settled, we see the incumbent Labor government maintained its office but has constructed a super portfolio.

The Association was one of many service provider organisations that supported the Disability Alliance campaign during the election. The Disability Alliance established a website and materials to empower Queenslanders with a disability to participate at the local level in the campaign. The focus of the Disability Alliance was to seek positive outcomes for three early intervention outcomes namely: personal care support, equipment and aids, appropriate health care in hospitals and community health settings.

The election was a strange one with the short time frame, which telescoped activity as the Disability sector competed for opportunities, and the policies on disability from the parties came late. The LNP, Greens and Family First ultimately presented their disability policy, but Labor did not - other than to state it would spend \$3 million on a congregate care building on the Gold Coast.

The Disability Alliance launched its election campaign at a public event in Brisbane followed by similar public events in Townsville and Bundaberg.



**The Hon. Ms Anastacia Palaszczuk,  
MP, Minister of Disability Services and  
Multicultural Affairs**

People with a disability, carers, advocates and service providers engaged in a rally outside the State Parliament. The Disability Alliance campaigned on the theme of: 'Fix Queensland's Disability Disgrace'.

With the ALP victory there is a new set of Ministers sitting in government, and Anastacia Palaszczuk has been appointed Disability Services and Multicultural Affairs Minister. Ms Palaszczuk served in the portfolio for a period of time under former Minister, Warren Pitt.

The Premier has elected to construct a new portfolio framework whereby Disability will sit under the global portfolio

heading of Social Development.

We look forward to working with the new Minister and her team.

From her initial meetings since taking office, the Minister seems keen to tackle the portfolio, and has indicated her willingness to consult. Most of all we need reform.

This is necessary because the disability sector will not be willing to sustain another three years based on the past.

As the Disability Alliance said to the Premier in a letter, when community defies government, both sides know change is required. This election process made it patently clear that change will be inevitable.

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# A Charter of Rights: that is the question

Marion Webb, Information Officer

## National Human Rights Consultation Committee

A charter of rights once set into the Constitution is a strong legislative document that protects the rights of all people, cannot be infringed by government, and in particular can only be changed by a vote of the people. A Charter of Rights is seen as "the line in the sand" over which politicians and bureaucrats cannot move to change legislation or policy that reduces people's rights.

The United Nations Convention on the Rights of Persons with Disability (CRPD) was ratified by the Australian government on 18 July 2008. Whilst the Australian government agrees to the principles of the CRPD it is not legally bound to uphold them until they are included in Australian law. Australia is the only democratic country in the world that does not have a Bill or Charter of Rights, and as long as this situation continues, the government cannot extend the Rights in the CRPD to persons with disabilities.

Currently the Federal Government has begun asking Australian's whether they think a Bill of Rights would be a good idea for Australia. A National Human Rights Consultation Committee has been consulting across the nation, hearing stories from all those who have experienced human right abuses, including people with disabilities.

Submissions can be made as part of the consultation up until 15 June 2009. To support all those who have submitted stories and evidence of abuse, Queensland Advocacy Inc. (QAI), has met with other like organisations and retained a human rights lawyer to formulate a submission as part of the consultation process, articulating a strong policy position on the need for an Australian Charter or Rights, that encompasses supporting reasons why such a charter should be incorporated into the Constitution. Other organisations are called upon to support the submission by communicating evidence of human rights abuse of people with disabilities. People with disabilities, their families and friends are called on to also provide the consultation process with evidence of examples on how their human right has not been met.

The Spinal Injuries Association encourages you to think about the following three statements, and then respond to them.

1. What does human rights mean to you
2. Do you have a story or stories where your human rights were not met, and
3. How could Australia better meet your human rights

Send your submission in support of your human rights to:

**National Human Rights Consultation Secretariat  
Attorney-General's Department, Central Office  
Robert Garran Offices, National Circuit, BARTON ACT 2600  
or submit on line:**

<http://www.humanrightsconsultation.gov.au/www/nhrcc/nhrcc.nsf>  
and click on Share your views



# From the CHAIR

David Riley, President

## Strategic Planning Workshop

The strategic planning workshop was held 30 - 31 January. There was an emphasis on how best the Association can support member needs, and the group engaged in strong discussion regarding areas to concentrate on over the next three years. Once agreement was reached, a focus group was established for each identified theme to develop strategies and actions to ensure success.

The brief for each focus group was to meet and achieve the following:

- Agree a single vision - three years, for each theme.
- Develop specific goals and potential measures.
- Suggest specific initiatives and actions.
- Identify potential challenges.

The focus groups reported back to the planning team and there appears to be general consensus supporting the proposals. This is still very much work in progress, but I can inform you on our thinking, and below, give you a brief summary of each theme so far:

**1. State Coverage:** All people in Queensland with a spinal cord injury can receive greater access to services.

There was agreement that the Association needs to focus more on achieving 'greater equitable access' to all services for all people in Queensland with a spinal cord injury. Given the size of the State and the location of members, the Committee is aware that to use a bricks and mortar approach is not the answer - a range of strategies utilising modern technology must be considered.

**2. Profile:** An Association that is recognised and respected as a leader in the broader community.

There is a need to continue to raise the Association profile. We must further develop the new website; communicate better with stakeholders; look for branding opportunities; extend the SEAT program, and increase media coverage - all within well considered financial constraints.

**3. Business Model:** A clearly defined Business Model that maximises income in three areas:

- Government funded services
- Commercial activity
- Community fund raising

The Committee is well aware of the increasing pressure on funding from all sources, particularly in the current economic environment. Accordingly, we need to maximise income from the government, corporate and the broader community.

**4. National Alliances:** Have developed a national voice on issues, which enhances the lives of people with spinal cord injuries.

The success of the Disability Alliance in Queensland has proved that the combined approach to specific issues by like minded individuals and organisations can be more powerful than just a single voice. We need to identify other organisations with similar values and establish alliances with these groups. Through these alliances we will also be able to share information and resources and advocate on appropriate policy and models of service.

In conclusion, this brief summary identifies the ideas discussed. There is still a lot of work to do in order to finalise our strategic plan.

I would like to thank all the management committee and senior staff for their input and support throughout this whole process. We could not achieve quite as much without the joint participation of all.

## Changes in the Management Committee

I have the rather sad job to inform you that in March this year Judy Collins resigned from the Association's Management Committee. Judy has been on the committee for the best part of ten years and done a fantastic job. On behalf of the Committee, the Association, its staff, and particularly the members, thank you Judy - we wish you all the best for your future endeavours. I know Judy plans to continue her significant involvement in disability issues.

Committee members are elected by the general membership at an AGM and serve for a period of two years. When a Committee Member resigns it creates a casual vacancy. In these circumstances, the Committee then has the authority to appoint a person to fill the vacancy until the next AGM. When the Committee considers who would best fill a casual vacancy, an audit of the skills and experience of existing Committee members is completed to identify what other skills and experience are needed to maintain a strong, proactive and dedicated Management Committee. In addition, as a Queensland wide organisation, an importance is placed on regional representation.

Accordingly, the Committee has appointed Ian Chill (Cairns), Vicki Field (Brisbane) and Mark Dillman (Brisbane) to fill the three casual vacancies. The next edition of Imprint will include profiles of the new Committee members.

## Disability and the Queensland Election

There is no doubt that the disability issue was strong on the agenda of some political parties leading up to the recent Queensland election. Media coverage in the latter stages showed that the issue was being taken seriously in some areas of the election campaign. The Disability Alliance had an impact due to the coming together of so many interested parties.

Engagement across the sector was strong – there were launches in Brisbane, Bundaberg and Townsville. Two rallies were held in Brisbane – one organised by the Disability Alliance and one by the Queensland Safeguards Coalition. Their messages were similar and the need for reform and additional funding are the same.

Some of the political parties responded with good policy platforms, clearly listening and wishing to address the appalling state of the disability sector in Queensland. Unfortunately, the Bligh Labor government's disability election policy was non-existent with only one announcement, which was to provide \$3 million in capital funding for a congregative care facility on the Gold Coast. This is a disappointing decision given the strong messages that have been conveyed to the government about the inappropriateness of co-tenancy arrangements, congregative care models, institutions and anything else that creates environments for people to reside where they are not empowered. One can only think the decision was political.

If the re-elected Bligh government does not respond to the sector's calls for change, as they have clearly been sent and heard strong messages from the sector, they will not be acting in the best interests of people with a disability. A number of candidates, including those recently elected, responded to the correspondence forwarded to them. Many did so with great enthusiasm and interest, while a few were clearly wanting in their knowledge of issues that people with a disability and their families face on a day-to-day basis.

The up side is there is strong momentum for the desire for change in Queensland; let's hope the government is up to the task.

### The Disability Alliance's three focuses remain:

- All people with disability living in Queensland are fully supported to live the same life as any other Queenslanders.
- The Medical Aids Subsidy Scheme be reformed to deliver aids and equipment in an affordable, equitable and timely manner.
- Reform of Queensland hospitals' patient care policy and procedures to include people with a disability and their families.

The focus of the Disability Alliance won't change. I feel very confident given the momentum gained to date that there will be stronger relationships and determination to influence governments at all levels, to fix the disgraceful



# Ins and OUTS

Mark Henley, CEO

position that exists.

If you are interested in being involved in the Disability Alliance, I encourage you to visit the website ([www.disabilityalliance.org.au](http://www.disabilityalliance.org.au)) and register your interest.

## Do you have adequate personal support? What about your equipment needs?

In the last issue of Imprint, I encouraged people to register their needs for personal support with Disability Services Queensland. It is important that if you have a requirement for additional support, or have no support at all, that you register your needs. It is also important that you put in applications for your equipment needs as well.

While the Medical Aids Subsidy Scheme is operating better administratively than ever before, the funding that is available for the scheme is appallingly short of what is required to support individuals needs. The cost of equipment, in most situations, with the subsidy offered is well below most people's capacity to fund. It is important that everyone's needs are registered. If you require assistance, please contact the Association.

## Australia Post delivers the goods

It is tremendous to see how the motivation of a small number of people can create so many opportunities for this Association. Tim and John Felhaber are clearly passionate about injury prevention and the SEAT program. Tim has been a volunteer SEAT presenter for four years and John, Tim's proud dad, as well as Tim's mum Kay and sister Danielle, have been supporting Tim to present at schools across southern Queensland in this time. John and Kay both work at Australia Post and when the opportunity arose to raise funds through Australia Post's 'Be Seen in Red and Green' day, John put all his energy into promoting the Spinal Injuries Association as a more than worthy cause.

Recently the Association received a cheque for \$27,000 from Australia Post as it was one of the four charities they chose to support in this state-wide fundraising initiative. You have to applaud Australia Post and their staff for the tremendous result, raising \$108,000 throughout Queensland - a significant contribution to the community. Australia Post's support is most appreciated and our sincerest thanks to them; to the Felhaber family, we are eternally grateful - it is great to see how the motivation and initiative of some can create such great outcomes for many.

# BITZ

John Mayo, Manager, Community Relations

## Committee resigns

The State Planning Committee responsible for Disability Action Week (DAW), which has run the Week for more than 10 years, took a vote in early February to dissolve. The Committee was unable to reconcile DSQ's handling of last year's event. It is not known if DAW will be continued by Disability Services Queensland.

## Public housing complications

A mature age female member residing in public housing has been subjected to harassment and vile behaviour over many months by two alcohol fuelled males in the same block. One would think that given the contract which underpins the right to access Public Housing, the Department would be able to exercise an eviction of unruly tenants, but in fact that occurs by application to a magistrate, which takes time. Following advocacy on the matter, the Association is pleased the Department has resolved the issue by shifting our member to a new location.

## Co-tenancy talks

Just days before the State election polling day, the Community Safeguards Coalition met with a disability senior policy advisor in Brisbane and put co-tenancy squarely on the table. Post meeting, Deputy Premier Paul Lucas responded in writing saying it was not the government's intention to have forced co-habitation and a meeting will be convened post election to resolve issues. None too soon for people with a disability, for as a member in Rockhampton said recently, 'co-tenancy is just another word for institutionalisation'.

## Kingaroy parking

Members in the Kingaroy region who use the Kingaroy Shopping Centre complex will see five undercover disability parking bays have become available. This is in response to a member of the Association raising the issue following a re-development of the site.

## Access to premises standard draft

The Association is making a submission to the Parliamentary Review Commission on the draft Standard. We are concerned that the draft has a number of areas that require change in order to deliver appropriate outcomes, including the fact that the draft will not meet Article 9 of the UN Convention on the Rights of People with a Disability.

## Hotel refusal

A Cairns member is being supported by the Association to lodge a complaint against a hotel for refusing her access to the premises to meet friends inside, late one morning. There was no drinking involved, it was the middle of the day, and yet management refused to give a reason why she was denied access. As a result, this matter is being opened up through the Anti-Discrimination Commission.

## Transverse Myelitis Awareness Day

Transverse Myelitis (TM) is a neurological disorder which causes inflammation of the spinal cord, and can cause degrees of paralysis. Transverse Myelitis Awareness Day on 17 May 2009 is cause for the Association to launch a campaign in the media to draw attention to the condition, and alert the community to its existence, which is not a commonly recognised disease, but can afflict any person unknowingly at any time.

## New Website

The Association's website has been through a major revamp both technically and in format and can now offer many new services, information and news. The Association asks members to trial it and provide feedback.

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# Post Polio Support

## Sunshine Coast

**Convenor: Cathy Newman,  
5447 6608 Email**

**[cathynewman@tadaust.org.au](mailto:cathynewman@tadaust.org.au)**

**Group meets on first Friday of the month at 10am.**

With the planning period for 2009 upon us, the Sunshine Coast Support Group had their first meeting for the year in February, and many varied suggestions were discussed with the intention to keep the Support Group busy in 2009. The group will have a mix of social, information gathering and guest speakers. At the March meeting members will discuss the information each has gathered re services in their respective area, such as community services, business places, and others who offer assistance with shopping, prepared meals, home delivery etc. The geographic area of the Sunshine Coast Group covers from Bribie Island to the coastal and hinterland areas, north to Cooroy. This exercise of information gathering should be very informative and beneficial for everyone. Networking is the name given in the business world, well we are doing our own "networking". As our usual meeting place is not available again for March, the group will take advantage of the change of venue and make this a group meet, as well as a morning tea outing, followed by lunch for those who choose to participate. The February Meeting was held at a relaxing property amongst the trees. The need for the technical eye from one of our male members was required when the battery of one of the ladies cars decided that the day had come to call it quits. The mixture of meeting, shared lunch and mechanical intervention made for an atypical day. The final planning for 2009 will be completed at our March Meeting, so as members can make their diary entries for the year. We endeavour

to have a productive year in all ways in the support of each other. Go safely and carefully, in support of one another.

## Brisbane

**Convenor: Hugh Banney  
3355 3298**

**Email [hughban@dodo.com.au](mailto:hughban@dodo.com.au)**

**Group meets at 2pm on April 4, at Spinal Injuries Association, 109 Logan Rd, Woolloongabba**

The hot humid weather took its toll on the attendance at our first meeting of the year in February, however, twenty-one brave souls enjoyed the comfort of the air conditioned meeting room.

It was an interesting afternoon with plenty of thought provoking information from members and invited speakers. Ann Rahmann from University of Queensland Health and Rehabilitation Clinics provided some interesting information on the management of the late effects of Polio, and the assessment services and treatment available at the clinics.

John Nightingale from the Rotary Mt Gravatt Club gave details of Rotary Australia's major fund raising drive to support the International program for the eradication of Polio worldwide.

Our unofficial patron, Jenny Horton on the eve of her departure to Nigeria for a three month voluntary stint as a member of a polio eradication team, supported John's announcement that funds raised would help to match the Bill and Melinda Gates Foundation further offer of \$255 million. On hearing this report the meeting unanimously agreed to donate \$100.

Our next meeting will be on Saturday, April 4, and thereafter bi-monthly on the second Saturday of the month: June, August, October and December. The group continue to be actively involved in the Post Polio Survey.

A sub-committee was formed to

look at the group's needs, such as personal support and social activities.

## Gold Coast

**Convenors Lyn Glover  
5520 6856.**

**Email [lyn.glover@hotmail.com](mailto:lyn.glover@hotmail.com)**

**Graeme Johnson 5564 6276.**

**Email [graron1@dodo.com.au](mailto:graron1@dodo.com.au)**

**Group meets on the first Monday of each month at 10.30am**

**Contact convenors for venue**

It was great to have a good turnout at our first meeting for the year, and to especially welcome a new member and her carer to our group. Catching up with friends and sharing stories of our comings and goings over Christmas was a highlight.

The group decided on some guest speakers for the year such as Life Tec, COTA and to also tap into our own Association Occupational Therapist. We are all off to a great start for the year.

If you have never been to one of our meetings we extend to you a very warm welcome.

## Cairns

**Convenors Joy Hay 4055 5795**

**Email [joyspider@bigpond.com](mailto:joyspider@bigpond.com),**

**John Heineman 0411 638 712**

Questionnaires have been sent out to Cairns members and several replies have been returned, thank you. For those who have not yet replied, we would really appreciate it if you could take the time to fill the questionnaire in and return it to assist us to deliver a relevant and meaningful meetings for members. Our next meeting will be on the March 24, between 2 - 4pm at the Cairns library.

A dietician from Queensland Health will be the Guest Speaker at this meeting.

**Continued page 7**

**Marion Webb, Information Officer**

## **Companion card**

The Companion Card is here!! As you know the Companion Card has been in the wind for some time, and has eventually made the distance and landed in Queensland, with applications now being accepted. The card is aimed to bring opportunities for people with disabilities who require carer support to participate in recreational and social activities by providing a two-for-one ticketing system into participating events. The national Companion Card website [www.companioncard.asn.au](http://www.companioncard.asn.au) provides further information including application form, and cardholder handbook. Alternatively, telephone 131 304 or email [cardservices@smartservice.qld.gov.au](mailto:cardservices@smartservice.qld.gov.au)

## **Local Government: Report a maintenance problem**

Brisbane City Council has initiated a 'Report a maintenance problem', whereby they encourage residents to report a problem that needs fixing in your street, local park or neighbourhood by completing a Fix-o-gram or Pix-o-gram, see website: [http://www.brisbane.qld.gov.au/BCC:BASE::pc=PC\\_2081](http://www.brisbane.qld.gov.au/BCC:BASE::pc=PC_2081) The intention is that problems such as rubbish, e.g., lots of litter in a park or on the roadside; graffiti e.g., on Council buildings or park facilities; park maintenance e.g., broken furniture, damaged signs, overgrown grass or leaking tap in a park; road or footpath maintenance, e.g., damaged footpath, kerbs or gutters, potholes, overgrown grass on roadside, or damaged street signs;

stormwater drain maintenance – blocked stormwater grates. Of course, these maintenance problems can also be advised by phoning or emailing Council. If you are not a resident in Brisbane, you can certainly phone or email your local Council if you notice any of the above in your area. Perhaps we should introduce new slogan: 'Tidy-up Queensland'?

## **Big and easy mobile phones**

Member, George Dougherty, always on the look-out for new and innovative assistive equipment and services, has alerted me to a new bigger mobile phone that is set to hit the market soon. The phone has big clear numbers, high-contrast backlit screen that displays large text size, as well as a large backlit keypad that make the numbers easy to see and use. This Ezy phone has attributes that members would probably welcome. I have been advised that the bigger mobile phone will be released sometime in April 2009, and we look forward to receiving further information on supply outlets in Queensland.

If you would like any further information on this new inventive mobile phone see:

<http://www.oricom.com.au/product.asp?prod=312>.

## **Adaptive clothing**

A representative attended the Brisbane Member Network meeting with an adaptive clothing range to show to members. The representative explained they have been producing clothing to suit specific needs since 2006. For more information: [www.specialcareclothing.com.au](http://www.specialcareclothing.com.au)

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## **Post Polio Support** continued...

### **Townsville**

**Convenor Mary Gibson**

**4779 8838 Email:**

**[emarygibson@bigpond.com](mailto:emarygibson@bigpond.com)**

**Group meets bi-monthly on the first Sunday of the month at 2pm**

It has been quiet over Christmas and the wet season, however, the first meeting for the year in February went well. General discussion was held around a book called 'Living with Post Polio' which is proving to be very popular, and also courses offered by 'University of the 3<sup>rd</sup> Age'. Next meeting will be the first Sunday in April.

Everyone brings a plate to share. Contact Mary for more details.

### **Toowoomba**

**Convenor Rev Brian Sparksman**

**4632 8835 Email:**

**[achance@twb.catholic.org.au](mailto:achance@twb.catholic.org.au)**

**Group meet on the second Thursday of the month at Lourdes Activities Room, 227 Spring Street, Toowoomba.**

Our first meeting for 2009 was attended by a large group of members who met to hear Dr Peter Nolan speak on "The present state of research into Post Polio Syndrome". Dr Nolan suggested

that it is time to advance the research that he did some years ago on Post Polio Syndrome. The Toowoomba Post Polio Support Group requested him to undertake that further research on their behalf. Group members indicated that they would be happy to partake in the research by submitting their polio history and by undertaking a physical examination. Dr Nolan indicated he is happy to do the research, but that he would first need to arrange permission of the project by the Toowoomba Hospital Ethics Committee. He will let us know later if it has been approved.

# Rehab for Incontinence solves two problems

Linda L Bieniek, CEAP  
(retired), La Grange, Illinois,  
[lindabieniek@sbcglobal.net](mailto:lindabieniek@sbcglobal.net)

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I have suffered from urinary incontinence (UI) for more than ten years. This condition, often uncomfortable to discuss, disrupted my life and distressed me. Recently I have gained incredible relief from UI – about an 80% reduction of symptoms – by participating in the Pelvic Rehabilitation Program at Loyola University Medical Center in Maywood, Illinois. As a surprise bonus, I also have resolved constipation problems that I had struggled with since childhood. I hope that the positive results I have achieved will motivate other polio survivors with UI and bowel problems to pursue treatment that can improve their lives.

## A Slow Start

Studies claim that women usually do not seek medical intervention for UI until three years after the problem begins. Unfortunately, I beat that record. My incontinence problems started around 1995, but I did not consult a urogynecologist until 2000. At that time, Linda Brubaker, MD, prescribed physical therapy for “stress and urge incontinence.” Regretfully, I never followed up because I was too busy. By 2005, I had “urge incontinence” that made me void every 15-20 minutes in the mornings. But I still did not revisit Dr Brubaker. The next year, after an unrelated surgery and months of catheter use, my problem escalated. Certain activities, such as suctioning my tracheostomy or pouring liquids, triggered stress incontinence. I felt the urge to void more frequently. Although I always wore a maxi-pad, at times, the leakage was excessive. I could not go out without fear I might have an embarrassing accident in public.

## PHASE 1: Assessment & Diagnosis

In 2007, I finally returned to Dr Brubaker at Loyola University Medical Center for another consultation. Fortunately, she understands post-polio syndrome and has treated other polio survivors. Before meeting with her, I completed paperwork that asked about my experience with UI, bowel functioning and sexual activity problems. On one form I prioritized the problems by how severely each interfered with my functioning, and also, by the order in which I wanted to resolve them.

During the consultation, Dr Brubaker first tested to see if I emptied my bladder when I urinated. I had no problem with that. Then she performed an internal examination of my pelvic muscles to assess their strength and check for problems such as a tumor that could cause incontinence. Determining that my pelvic muscles were weak, she referred me for pelvic muscle therapy and prescribed Ditropan® (oxybutynin chloride), an older inexpensive drug to help with the urge incontinence.

## PHASE 2: Physical Therapy

After I scheduled physical therapy appointments at Loyola University's Pelvic Rehabilitation Program, I received information clearly outlining the various treatment options of this program. When I arrived at the clinic, I completed a comprehensive medical history and answered questions about my incontinence patterns.

After reviewing my data, the physical therapist, Heather, explained each step of the treatment process. She began by internally examining the strength, flexibility and control of my pelvic floor muscles, and then, manually stretched them. Initially, the stretching process was painful, but the pain subsided with each subsequent session.

Heather taught me exercises for strengthening my pelvic muscles. I learned how to contract them for a set amount of time and slowly release them

to control the flow of urine. Each week, she also gave me paperwork to complete.

## PHASE 3: Bladder & Bowel Assessment

My homework was to track the liquids I drank, the food and fiber grams I ate, days and times I voided and had bowel movements, and the texture of my bowel movements based on a form identifying five different textures. In assessing my paperwork, Heather found that I ate plenty of fiber, but needed to drink more water. She gave me a list of liquids and foods that trigger urinary urges, such as coffee, tea and tomatoes, but she did not think that drinking two cups of tea each day was the cause of my excessive urges.

Noting that I experienced frequent constipation, Heather explained that my bowels could be pressing on my bladder, contributing to my UI. I realized that I had struggled with constipation since I had contracted polio as a child. I remembered that while I was in the hospital encased in a full-length body cast and undergoing surgeries, I dreaded receiving enemas even though they relieved the discomfort from being constipated. As an adult, I ate prunes in addition to a high-fiber diet and sometimes used herbs, but I was inconsistent in managing my bowels.

## PHASE 4: Another Door Opens

During the weeks that Heather stretched my pelvic muscles, I practiced the pelvic floor exercises and took Ditropan®. As I still had UI symptoms after the four treatments allowed by Medicare, she referred me to Judith Meredith, OTR, who uses biofeedback training as part of the Pelvic Rehabilitation Program.

## Definitions:

- **Urinary Incontinence (UI)** is loss of bladder control that occurs because of problems with muscles or nerves that help to hold or release urine.

• **Urogynecologist** is a physician who specializes in urology and gynecology and treats women with urinary, bowel or sexual problems.

• **Void** is another term for urinate.

**Biofeedback** is the process of using measuring devices to help a person become aware of body functioning. Electrodes and probes connected to a computer program will show, on a monitor, when the bladder and uterine muscles contract, helping a person gain control over these muscles. Biofeedback can supplement pelvic muscle exercise and electrical stimulation to relieve stress and UI.

### TYPES OF URINARY INCONTINENCE (UI)\*

• **Stress Incontinence.** Leakage of small amounts of urine during physical movement or an activity (coughing, sneezing, exercising).

• **Urge Incontinence.** Strong urge to void, often when there is little urine in the bladder. Leakage of large amounts of urine at unexpected times, including during sleep.

• **Overactive Bladder.** Urinary frequency and urgency, with or without leakage.

• **Functional Incontinence.** Untimely urination because of physical disability, external obstacles, or problems in thinking or communicating that prevent a person from reaching a toilet.

• **Overflow Incontinence.** Unexpected leakage of small amounts of urine because of a full bladder.

• **Mixed Incontinence.** Usually the occurrence of stress and urge incontinence together.

• **Transient Incontinence.** Leakage that occurs because of a temporary situation (infection, taking a new medication, colds with coughing)

\* Adapted from the National Institute of Health's Medline Plus website

### PHASE 5: Conquering Constipation – The Miracle of MiraLax®

After reviewing my worksheets, Judith focused first on my constipation problems and recommended that I take MiraLax® (polyethylene glycol), which previously required a doctor's prescription, but now is available over the counter. She described how it

works in the digestive system and emphasized the importance of taking it daily; she also explained the negative aspects of the herb senna that I had been taking. Since following Judith's advice, I am astounded by the improvements in the ease, frequency, quantity and texture of my bowel movements. Until I had started using MiraLax®, I had lost significant time and energy and endured a great deal of discomfort during most of my life because of constipation. Now, I never miss a night of taking MiraLax®. In addition to reducing my incontinence problems, it has decreased the frequency and intensity of irritable bowel attacks, and has relieved pressure on my diaphragm, which helps my breathing.

### PHASE 6: Biofeedback Training – Another Miracle!

Next, Judith began using biofeedback to help me strengthen my pelvic floor muscles. First, she applied electrodes (as used for an EKG) to specific places on my body and then inserted a small sensor into my rectum (another option is the vagina), connecting these to a computer program. She showed me how the program graphed my pelvic muscle contractions and releases on the computer monitor. My exercises involved rotating periods of contracting and releasing the pelvic muscles with the goal of reaching a certain point on the graph. After three biofeedback sessions and practicing the exercises at home, I gained significant strength in my ability to contract, control and release my pelvic muscles. Judith was extremely pleased with how quickly I achieved results, noting that most people usually require more sessions. By participating in this program I have reduced both urge and stress incontinence incidents by an estimated 80%. I rarely have any leakage; most days I do not even need to wear a maxi-pad. Instead of needing to void every 15-20 minutes in the morning, I can wait 45-60 minutes between voids. And I have not had any more accidents. I continue to take Ditropan® twice a day because I feel it also helps.

### Research Findings

Most studies cited on the Internet have

concluded that using biofeedback in addition to pelvic floor therapy and exercises has improved the patients' outcomes. Based on the findings of independent studies, Medicare reimburses covered charges for pelvic rehabilitation physical therapy and biofeedback treatment when properly documented to meet Medicare protocols. However, Blue Cross Blue Shield has used other findings to justify refusing reimbursement for biofeedback. Pelvic rehabilitation treatment often is prescribed for UI experienced by women after pregnancy or during menopause; by men after prostate treatment; and by both genders after surgery, a stroke or for neurological conditions such as multiple sclerosis.

### Treatment Providers & Coverage

In making treatment recommendations, urologists and urogynecologists at major medical centres are most likely to have access to Pelvic Rehabilitation Programs and to refer their patients to physical and occupational therapists trained in providing services such as manual therapy and biofeedback for UI. Otherwise, polio survivors need to do research to find local professionals skilled in providing such services. The Association for Applied Psychophysiology and Biofeedback (AAPB) and the Biofeedback Certification Institute of America (BCIA) websites identify professionals trained in providing biofeedback, but their lists are limited. Another challenge for polio survivors is learning whether their health insurance will reimburse for pelvic rehabilitation services such as manual therapy and biofeedback. If it does, a physician's referral always requires proper documentation to justify the medical necessity of the service.

### Recommendations

I highly recommend that polio survivors with UI pursue treatment options such as pelvic rehabilitation by taking the following steps:

• Identify your urinary patterns and problems by tracking them for a period of time.

Continued page 10

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- Consult a urologist or urogynecologist who specializes in UI for a thorough assessment and treatment referrals. Inquire about whether pelvic rehabilitation therapy, including biofeedback, is an option for reducing your symptoms. Find out if your health insurance will reimburse for pelvic rehabilitation services including biofeedback. Commit to working with therapists and doing the exercises and homework required. Track your bowel movement patterns and seek assistance to resolve any constipation or diarrhea problems.

As polio survivors, we cannot change many aspects of our physical health. We can, however, seek treatment for reducing UI symptoms. I hope polio survivors will make getting help with this distressing condition a priority.

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Olympic diving medalist and Spinal Injuries Association Personal Care Assistant Robert Newbery inspired staff with his achievements at the "Focus on what makes the difference" seminar

# Olympian inspires staff with sporting and study achievements

Megan Illmer, Communications Officer

His precision diving and Olympic accolades have made Robert Newbery a well known Australian athlete, but he is also on his way to becoming a doctor, and is a dedicated Personal Care Assistant (PCA), husband and father.

In February, Robert shared his story on how to effectively set and achieve goals at the Spinal Injuries Association's "Focus on what makes the difference" staff seminar.

Robert, who is just a over a year away from finishing his medical degree, has three Olympic bronze medals, and a gold; two silver and two bronze Commonwealth Games medals, not to mention countless other titles to his name,

To fit around his studies, sporting and family commitments, Robert has spent the past two years as a Spinal Injuries Association PCA.

He shared with Association staff how he managed to organise his time effectively and stay motivated to achieve sporting and academic success, as well as maintain a strong family life with his wife Chantelle, also a former Olympic diver, and their two young sons.

Spinal Injuries Association CEO Mark Henley said Robert's dedication in the sporting arena, professionally and in his family life was hugely inspiring to staff.

"At just 30 years of age, Robert has achieved so much and in his future medical career I'm sure he will continue to inspire and assist people," Mr Henley said.

"We're extremely proud to have Robert as one of our PCAs. His role and that of all PCAs is vital in ensuring our members are assisted and empowered to live as independently as possible."

# Adjusting to spinal cord injury

Col Mackereth, Peer Support Coordinator

*10 tips for people who have newly acquired spinal cord injuries from someone who has "been there – done that" with C6 quadriplegia for over 30 years.*

1. Don't sweat it too much now – it actually does get easier and you do learn to cope.
2. Forget everything you knew about disability prior to your injury. You are now on the steepest learning curve of your life. Don't believe everything you hear in hospital as gospel. Give some consideration to most of what you hear in Rehab. Question "how will this effect me?" and "does it fit my lifestyle?". Process everything well before you swallow it.
3. Live in "the now" and get on with your life the way things are right now. Don't become obsessed with a "cure". When a reliable treatment is found you will hear about it, trust me.
4. You're not Robinson Crusoe. You don't have to do it alone. Seek out someone living successfully with a similar injury and lifestyle to you and learn from their experience. Most people with a SCI are eager to help.
5. Don't let go of who you are spiritually, intellectually, affectionately and emotionally. That person is still in there and still has the same capabilities.
6. Push yourself to the limits of your strength and maintain high expectations of yourself. You don't have to be brave – just focused. Remember though, you don't have to prove yourself to anyone but you.
7. Strive for "normality". Continue to support the Broncos, the Reds or the Bulls. Maintain your interest in a hobby or pastime. Go out clubbing or pubbing. Get involved with family and community activities.
8. Get intimate with your partner (or go out and find one). There are five senses involved in making love; touch, taste, smell, sight and sound. Just because you can't feel it doesn't mean you can't taste, smell, see or hear it. The way I look at it 4 out of 5 ain't bad. And that's just the physical side.
9. Gather information and services from every source possible. There is a plethora of internet sites with helpful information (remember tip 2 though). There are also many and various services and benefits that you may now be entitled to. Use them! It is your right not a privilege. Try not to be put off by the red tape.
10. You are not a second class citizen and have the same rights (and responsibilities) as everyone else. You are entitled to equal access, respect, opportunity and belonging. Remember your rights because at times you may have to fight for them.

**Participate fully in whatever happens in your life. You are still in control of your own destiny.**

**Your disability is not a good enough excuse. If you don't like the way things are – CHANGE THEM!**



## NEW PEER SUPPORT OFFICER

**Katie Franz, Peer Support Officer**

My name is Katie Franz and I am very excited to introduce myself as the newest member of the Peer Support Program. To have the opportunity to empower members of the community who have sustained a spinal cord injury, with knowledge and a better understanding of what life can provide and be is a role I am eager to succeed in.

I severed my spinal cord in a car accident, which left me with L1-T12 paraplegia. When I was confronted with such a life changing event at the age of 16 it was not only traumatic for me, but for all those around me. Since that day, I have pushed the boundaries of disability on a daily basis. Living by the motto "life is 10% what happens to you and 90% how you choose to react", I continue to change people's perception and prove that disability is not the end of a beautiful, fulfilling and happy life.

I have worked as a Teachers Aide in a Special Education Unit, teaching life skills to children with a variety of disabilities. I went on to study anatomy, physiology, exercise science, fitness management and medical terminology making me an informed Personal Trainer, after which I went on to manage the very college I undertook my study. Most recently I have been a guest speaker for trainee nurses, Occupational Therapists, Physios and Carer's helping them to explore and discuss the ways and means of adapting to life after a spinal cord injury.

My experience in the industry is purely from life's lessons and experiences that I have lived in the last 13 years. I am married and I have two beautiful children, which are by far my greatest accomplishments.

# International speech contest

PRESENTED 13 OCTOBER 2007

Jack Kennedy, Member and Toastmaster

“LEGS OR WHEELS!”

Madam Contest Chairman, fellow Members and guests.

You all know what a PALINDROME IS! “Madam, I’m Adam!” is a palindrome, another is the Napoleonic one: “Able was I ‘ere”, I saw “Elba”.

Ladies and Gentlemen, meet my constant companion: “Elba”...she doesn’t have very nice legs, but she has 4 wheels, just like your car, yet you and your family members rely as much on a car as I rely on “Elba”. You certainly travel much further on your wheels than I DO ON MINE! Then again, your car won’t fit in a bus, but with the accessible busses now, “Elba” can! She frequently takes me on a bus or a train, and she has an official number plate just like your car which allows her to take me on the road where there are no footpaths.

Now, “how many of you have functional LEGS?” Are you relying on your wheels too much and not using your legs enough. Remember, “If you don’t use it, you lose it!” Reliable statistics are hard to find, but my research revealed there are about 12 to 13 thousand people with paraplegia in Australia, but that doesn’t show WHEELCHAIR USERS - there are all the other conditions like Multiple Sclerosis etc. One statistic says there are about one and a half million disabled and elderly in our country. I’m not one of them... I’m both - officially, that is. I’ve been paraplegic from a back operation for 34 years and next March I’ll be 76, but, I don’t consider myself either disabled or

elderly, but I’m very LUCKY! Every one has a different story. What a great life I had before I received my handicap!

Briefly, I had a great barefoot childhood in North Queensland. I went to boarding school for three years in Brisbane, joined the bank in Texas - my Dad was the Head Teacher there, and I went on the Relieving Staff for six years in Queensland, Victoria and New South Wales. I sailed to London on a Dutch ship in 1959 through New Zealand, Tahiti, Florida, New York, and Southampton to London. I worked at the West End, The Strand and Tokenhouse Yard in the city branches of the National Bank of Australasia.

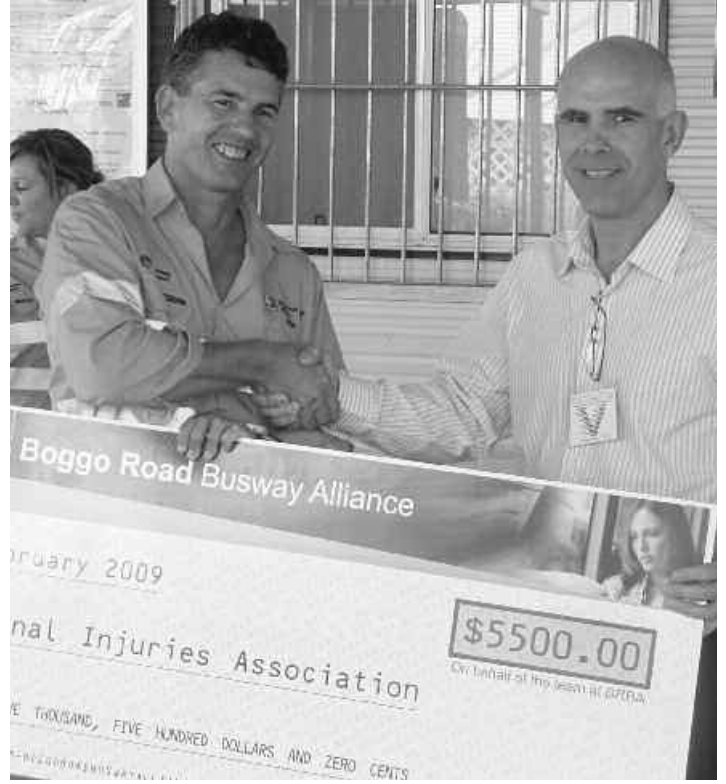
I was the foreign Teller in the West End. One of my regular customers, Barry Humphries, was made a C.B.E. by the Queen a few years ago. London needs a whole book! Then to Germany where I alternately starved and partied, learnt a little German “Ein bishien” selling Encyclopedias door to door. “Entschuldigen bitte Americanish family Wohen sie hiere?” I lived for short times in Paris, Rome, Munich, and Berlin. I went around Ireland twice; to Scotland as far as The Firth of Forth, then back through the Suez on the Oronsay, and home to Queensland. I was a “travelling man” and loved life and the people I met.

After becoming a Real Estate Agent and Auctioneer in Sydney where previously I was a Bank Teller, a Boxer, and had an Indian motorbike and side-car - this time I had an old \$3000 Mercedes. Then I married a Queensland

school teacher, Sandra; after two years we returned to Brisbane in 1969. Starting with nothing, I had two Real Estate offices at Stafford and Mitchelton, and ten staff by 1974. In August, I was in S7 learning to use a wheelchair. My family was supportive and my brother helped to build my house in Albany Creek where we still live. I opened an L.J. Hooker there in 1979 and had played wheelchair basketball; won a bronze medal in Swimming in the 1976 Games - there were only three in the race; joined Toastmasters, and sat for the State seat of Pine Rivers in 1983 winning by 5000 primary votes, only to lose on preferences by 161 votes! I was voted in to the Pine Rivers Council, I served three years in 1985-87. Later I sat for Mayor and lost - I had a good slogan though: “Elect a Mayor you can PUSH around!” My life has been full, before and after I swapped my legs for wheels!

In conclusion, life is a temporary condition - the other Jack Kennedy was only 46 when he died. I was in Berlin when he was there, and said “Ich bin ein Berlina” translated, I am a hamburger - a Berlin one. But when they take your passports at the Brandenburg Gate the young ‘vopos’ (guards), all came out to inspect me with big grins because of my same name. I called back “Ich bin ein cousina, Translated for me later “I am his {female} cousin - we don’t have gender in our word cousin”.

I have an “ENABLING DEVICE” - A wheelchair called “ELBA”. I AM NOT “wheelchair bound”!!!



Australia Post Queensland Commercial Manager Helen Brodie (far right) celebrates the \$27,000 that staff raised for SEAT with Spinal Injuries Association CEO Mark Henley (top left), SEAT presenter Tim Felhaber (front) and his parents Kay and John, who both work for Australia Post; and Boggo Road Busway Alliance Construction Delivery Manager Rob Hordern (left) presents Spinal Injuries Association CEO Mark Henley with their generous donation towards SEAT.

# Queensland workers fundraise for SEAT

Megan Illmer, Communications Officer

Thousands of Queensland workers have gone above and beyond the call of duty by helping to raise valuable funds for the Spinal Education Awareness Team (SEAT) program.

Hundreds of Australia Post staff throughout Queensland raised \$27,000 for SEAT as part of the Be Seen In Red And Green initiative.

Thanks to the recommendation of Australia Post employee John Felhaber, who is the father of SEAT presenter Tim Felhaber, the company nominated SEAT as one of four charities that employees supported over the course of a year, especially in the lead-up to Christmas. In total, Australia Post raised \$108,000 for the four charities.

"The generosity of Australia Post staff is much appreciated by our organisation, with the funds raised directed straight back into our award-

winning injury prevention program," Spinal Injuries Association CEO Mark Henley said.

"Boggo Road Busway Alliance staff have also been a great supporter of SEAT and we also extend our thanks to them for their dedicated fundraising efforts."

In February, the Alliance presented Mr Henley with a donation of \$7,500 towards SEAT.

The funds were raised largely from on-site vending machines as well as a commitment by Alliance supplier, Work Sense Safety and Workwear, to donate funds for the recycling of work gloves.

The Boggo Road Busway Alliance, which consists of Thiess, Sinclair Knight Merz (SKM) and Queensland Transport, is building the Boggo Road and Eastern Busway (Princess Alexandra Hospital to South East Busway).

# Disability Alliance – medical aids and equipment

Jordan Lefmann, Community Advisor

*Speech presented at a Disability Alliance public forum during the lead-up to the 2009 Queensland State Election.*

My name is Jordan Lefmann. I have been an occupational therapist for 7 years and solely been working in the community. I have worked in two different states of Australia; and both in city and regional / remote settings. My knowledge of equipment needs of people with disabilities living in our community is vast.

Equipment and aids are absolutely vital to making a difference in the lives of Queenslanders with a disability. The Disability Alliance calls for The Medical Aids Subsidy Scheme be reformed to deliver Aids and Equipment in an affordable, equitable and timely manner. As a person who is involved with the selection and processes involved of medical aids every day of my working week, I see strong evidence that things need improving. I would like to take you on a quick journey that is far too common with many of the people I see. This story is just one scenario but which in fact there are many scenarios of very similar situations all over North Queensland and this state which are happening right now:

I was approached 3 years ago by a person with a power wheelchair that was falling apart and in absolute desperate need of replacement. Following a comprehensive assessment, the person needed to trial several aids. In North Queensland we don't have readily available access to all equipment aids for trial. It took over 6 months before they had trialed three different chairs due to costs and logistical reasons. They were required to pay several hundred dollars for freight to get one of the chairs to Townsville because it was not a wheelchair that is on the MASS standard contract. This process in South Queensland would have taken two weeks and the person would not have been out of pocket. Once a selection had finally been made, the roller coaster ride of submitting the

request to MASS started. After waiting several weeks for an outcome, MASS offered to contribute approximately \$6000 towards the cost of the chair that was close to \$10,000. It took a further 12 months to secure some alternative funding. During this time the person suffered depression, required medication and lost interest in participating in their community. Finally three years later the person received the equipment they should have received three years earlier. They have been scarred by the process for life.

I would like to challenge our government to think about the provision of appropriate aids and equipment as an early intervention outcome. There needs to be a shift from being re-active to pro-active. People are going without equipment which is imperative for their health; because they can't afford the ever increasing gap between the government's contribution and the cost of the equipment. MASS won't often repair their old equipment if it tends to be over five years old. This places them at risk of injury or they are forced to purchase a much less expensive item which will not meet their needs in the long term. Take for example, a person who is an active wheelchair user. MASS only currently funds \$1200 for a manual wheelchair. Let me advise you that our shoulders were never designed to propel a wheelchair. A \$1200 wheelchair will pretty much provide something that is heavy, bulky, and difficult to propel and manoeuvre over distance and generally require more repairs. What most of the people who I see require, is an absolute minimum cost of \$2500 and possibly up to \$6000. This isn't equipment with bells and whistles, this is just lightweight options which preserve a person's bones and joints and keeps them out of hospital. This can leave a shortfall of over \$4000 that needs to be found. If policy is changed to recognise that wheelchair users require aids that are going to be less demanding on their body, last significantly longer without the need

for expensive repairs and be suitable for outdoor use as well as indoor use, then there are going to be positive consequences for all. If we want to keep people out of hospitals, and not make them fall into the sick role, correct equipment aids need to be provided. Three of the federal government's national health priority areas are arthritis, injury and mental health. Poorly fitted, cumbersome and unattainable equipment can easily feed into these three areas which goes directly against the Australian government's supposed vision for improved health for all Australians.

People need appropriate equipment in a timely fashion to access Centrelink services, their community and employment. In North Queensland our climate and topography is more demanding on equipment therefore it needs to be more suited and is often more expensive. The current Qld government's medical aids subsidy scheme does not extend to the needs of people who use their equipment primarily outside their home environment.

When we think of equipment it is not necessarily just mobility equipment such as wheelchairs. Hospital beds are not currently provided by the Queensland government in the community, yet they are in some other States. People who require them generally require personal care support. Without an appropriate hospital bed, the person who has a disability, their health may deteriorate and their carers are placed at unnecessary risk! If injuries occur, this costs the government more money. In Queensland, the current solution is nothing - people go without. This is not acceptable. I would like to leave you with one final point which is:

Early . . . intervention . . . outcome, will contribute towards people with disabilities progressing and improving OR going into a downward spiral and /or fighting just to keep on an even keel. This should be the governments focus.

# Things to consider when you are getting a new wheelchair

Bridget Barnet, Community Advisor

Manual Wheelchairs are used by a majority of our members and it is important that they are using equipment that is safe, adheres to approved standards and meets your functional need.

To provide you with further understanding how to choose a wheelchair, I have briefly outlined some principal consideration that one should take into account when deciding what wheelchair is for you. Each individual has different needs, so it is important to ensure you take into account your specific requirements and avoid assuming that, what suits one person in a wheelchair, will also suit you.

## Your Abilities

Make sure you acknowledge your diagnosis and prognosis, your style of propulsion (pushing) and your transfer technique to and from the wheelchair.

Consider your arm and leg length, your skin integrity and your endurance level. It is essential that you take into account your posture and what makes you feel comfortable. Think about if you need postural support, a head rest or additional back support.

It is necessary that you check if you are able to store your wheelchair in a secure area, and it is not going to impinge on available room within your home. It is also advised that you check how you are able to transport your wheelchair, and if you are able to maintain the wheelchair according to the manufactures instructions.

## Abilities of your Carer

If you have a Carer aiding your use of the wheelchair it is useful to consider the functional abilities of

your carer. Are they able to propel, dismantle, fold, lift and transport your wheelchair easily and safely? Is your carer able to facilitate your transfer to and from the wheelchair?

## Does the wheelchair fit your body

Ensuring that you have a wheelchair that correctly fits your body is essential to preserve your function, safety and comfort. To determine accurate fit, exact physical measurements of your body size is required. Occupational Therapists and Physiotherapists are trained to do this with expertise. The main measurements required for an appropriate fitting of wheelchair are;

- Seat width – chair must be wide enough so that it does not rub on your hips, but not too wide so that you are unable to reach the wheels to self-propel

- Seat depth – chair must be deep enough to provide good thigh support and distribute weight evenly throughout the seated area

Seat height and footplate height – hips should be at 90°, thighs parallel to the ground. It is estimated that there should be at least 5cm clearance under the footplate (this reduces the risk of the footplate bumping into gutters etc.).

- Armrest height – elbows should be at 90° when resting on arm rest, this supports correct shoulder position

- Backrest height – this is specific to a client's postural requirements, however it is usual for self-propellers to have back rest approximately 2-5cm below shoulder blade.

## The environment in which you plan to use your wheelchair

Make sure you test the access to

essential facilities within your home via wheelchair, as well as your ability to manoeuvre the chair in these areas. Does your wheelchair fit through doors within your home/workplace? Are you able to self-propel on carpet or rugs?

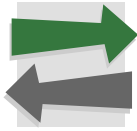
Using your wheelchairs outdoors on uneven surfaces, steep hills and for longer distance will impact on what wheelchair is suitable or may suggest that a powered wheelchair is a better option.

## Finance

Be aware of how much your wheelchair is likely to cost! If you purchase a wheelchair that does not meet accepted standards within Australia or does not 'fit' you correctly you may end up paying a lot more than the initial cost of the chair in ongoing maintenance and repair fees. It is also useful to remember the **cost to your body** should you have a wheelchair that compromises your safety.

Remember that it is estimated that you will use your wheelchair for several hours per day, so make sure you trial the wheelchair and really get the feel of it before you make any long term decision. There is no need to feel pressure to purchase a wheelchair that just doesn't feel right.

**The above information is a guide only. It is HIGHLY recommended that you seek professional advice from an Occupational Therapist or Physiotherapist prior to purchasing a manual wheelchair. This is important to ensure that the wheelchair chosen meets your functional need, maintains your safety for the foreseeable future and meets Australian, Universal, and European Standards.**



# Network news

## Brisbane

**Facilitator: Robert Montocchio 3379 4771; George Dougherty 3844 2949. Meets 11am, first Wednesday of the month at Spinal Injuries Association, 109 Logan Road, Woolloongabba**

The Network started the year with a social day in January where we enjoyed a mind challenging day with scrabble and Trivial Pursuit. With the social interaction during the games and during lunch a great social day was had by all and it was requested that another be organised for later in the year. This year we plan to have more communications with South Bank and the Brisbane City Council regarding the improving access to council park facilities. Ideas are always welcomed regarding places on interest to see, not too far away and inexpensive.

## Bundaberg

**Facilitators Luke Gale 4159 5668 Chris Grimes 4156 1639 Meets 10am, first Tuesday of the month at Brothers Club**

We had and a good time catching up with members at our first network meeting in February. We continued planning for our next meeting with Jack Dempsey MP, and John Mayo, Community Relations Manager, pending the election. 2009 will see us having active involvement in the region in the coming year. We are planning a large regional car cruise "Chrome Cruise" for Spinal Injuries Awareness Week, 8 -14 November. I encourage members to become more actively involved and have their say as I value your input. Looking forward to a great forum with our MP's on 3 March 2009.

## Maryborough

**Facilitator Peter Kalbefell 4121 7418. Meets 11am second Wednesday of the month. Contact facilitator for meeting venue**

We held our first meeting in February and had a fine time catching up with each other. At the next meeting

Bernice Quinn, Member Networks, and Belinda Kropp, Community Advisor and Occupational Therapist from Spinal Injuries Association, Brisbane will be presenting to the group. We look forward to you joining us on 18 March.

## Mackay

**Facilitators Alan Elliot 4954 8646 and John Smith 4959 3195**

**Contact facilitators for meeting places and times**

Mackay Member Network is meeting once a month for an informal luncheon and social gatherings. At present there is a core group of members that attend and they are keen to meet new members. A young member from the Mackay region is looking at gaining more independence in the community. He is a single man in his 20's with quadriplegia, and is considering buying a unit or house, and would like to know about any grants, funds, and modifications that could assist him in this process. If anyone could provide any information or assistance, please contact John Smith on 4959 3195 or email [jh2smith@bigpond.com](mailto:jh2smith@bigpond.com)

## Rockhampton

**Facilitator: Des Ryan 4926 4551, work 0417 775 365**

**Contact facilitator for meeting place and times**

Rockhampton Member Network has been moving ahead with the Inclusive Community Accord and pushing for Inclusive Communities Planning to be adopted by the Regional Council. The challenge is to ensure an audit is carried out, and then to maintain accountability, and make sure the planning and implementation of Inclusive Communities Plan occurs across all levels of the community. To this end the Rockhampton Network, together with the Council have called a workshop of Government Departments, (DSQ and Qld Health); varying professionals, and commercial business representatives, to discuss the

Inclusive Communities Planning. Key discussion points will be: develop a greater understanding of what Inclusive Communities are, the needs of Inclusive Communities and the importance of Planning for Inclusive Communities.

At this workshop Council will be releasing information around their policy and planning for inclusive communities. Key speakers at the workshop will be the Member of Rockhampton the Hon Robert Schwarten MP, who endorses the Community Accord, together with John Mayo, Spinal Injuries Association Community Relations Manager, together with Government and Council representatives, other key alliances i.e., Red Cross, QCOSS, Qld Alliance, Qld Health and Disability Queensland will share their plans. A focus group will form to carry this process forward.

## Tablelands

**Facilitators Grant Davis 4091 4784, Mark Taylor 4093 3821 and Russell Dafforn. Group meets every 6 weeks 11am in the Primary School Building. Contact facilitators for meeting dates**

This month we have been tackling a lot of parking access issues, in particular in the council park area and in reference for plans for modifications to the Atherton International Club. We have written letters asking them to consider these issues. We have also been discussing how we can encourage more members to attend meetings and have been considering more social outings.

## Cairns

**Facilitator Lynn Barnes 4055 6675 and Des Crowe 4032 3008**

**Meets the last Friday of the month. Contact facilitators for venue**

We are happy to welcome back Nita Carling who is soon to complete her training as a co facilitator. We plan to have our first meeting in March. We

## From page 16

invite you to attend our meetings and help plan the program for 2009. Flyers will be sent out soon.

Lynn was recently denied access at the Canecutter Tavern, and is pursuing the issue.

## Townsville

**Facilitator Scott Stidston 4783 1150 email [ssstidston@aapt.net.au](mailto:ssstidston@aapt.net.au) Townsville Member Network meets on the last Tuesday of every month. Contact North Qld office phone 4755 1755 for further information**

Townsville Member Network is meeting once a month with a core group of people and is looking to attract new members. A meeting will be held at the Kirwan Tavern on February 24 to brainstorm ideas to encourage more members to attend meetings. The new Member Networks coordinator for North Queensland, Rebekah Rowcliffe, has been surveying members for ideas on appropriate meeting times, and assessing the role of Member Networks in the community. If anyone would like to give Rebekah any input, please contact her on 07 4755 1755.

## Burdekin/Bowen

**Facilitator Scott Stidston 4783 1150 email [ssstidston@aapt.net.au](mailto:ssstidston@aapt.net.au). Phone North Qld office on 4755 1755 for further information regarding meeting times**

Facilitator Scott Stidston has been unwell for the last month, not to mention the difficulty around flooding, so not a lot has been happened in Member Networks meeting in this region. The Home Hill Crossing issue is still progressing, and they are still waiting to hear back on how it is all progressing. Scott attended a meeting with the Burdekin Health Network last week to talk on behalf of the Spinal Injuries Association, Spinal Education Awareness Team (SEAT) Program.

## Gold Coast

**The group will be facilitated by Bernice Quinn 3391 2044 until a new facilitator is in place.**

**Group meets 12 noon on the first Wednesday of the month for lunch and a meeting. Ring Bernice for venue details**

A very enjoyable meeting was held at the Gold Coast to acknowledge the work of co facilitators Neil Ashton and Cheryl Jacobs. Mark Henley, CEO, and Bernice Quinn spoke words of appreciation on Neil and Cheryl, who in turn shared some of the highlights of their time as leaders of the Gold Coast Member Network, especially with their work with the Gold Coast City Council, and the peer support they have shared with their fellow facilitators.



**Bernice Quinn, Senior Coordinator and Mark Henley, CEO, acknowledged the service of Neil Ashton and Cheryl Jacobs on their retirement.**

## Pine Rivers

**Facilitators Jimmy and Kay Considine 3283 8787**

**Meets 1pm first Monday of the month at Kallangur Bowls Club**

We wished everyone a big welcome and a happy New Year. We had a good roll-up at our first meeting with a presentation by LifeTec – “A great gadgets Exposition.” We had a very interesting time and we all gained helpful hints on the use of these gadgets.

New Issues raised by members were the ‘WALK’ lights on Anzac Avenue and School Road, which cannot be reached; no disabled parking at Eagle Farm Racecourse, which is being renovated, and too great a distance from the parking lot to the hydrotherapy pool at Redcliffe Leagues Club. The group has



suggested a Disability Service and Equipment Expo in north Brisbane including Kallangur – North Lakes, during Disability Awareness Week. This suggestion has been enthusiastically embraced by the Moreton Bay Regional Disability Network. We will keep you posted.

## Toowoomba

**Facilitator Wendy Adams 4637 4160 Meets third Wednesday of the month at 12 noon.**

*Alternates between a lunch time get together and update - next meeting March 18, and a formal meeting at the Toowoomba Council Chambers, Groom Room at 12 noon (next meeting April 15.*

Our first meeting at the Toowoomba City Golf club was enthusiastically attended by new and old members. It was good to see members excited about the Inclusive Community Accord and sharing the task of sending letters to people and organisations within their own networks. The newly amalgamated Toowoomba Regional Council has reduced its eleven access committees to seven, with the Network having a voice on the new “The Regional Access Sub Committee.” We will continue to address the Accord and look to the Council for an Inclusive Communities Plan. Toowoomba Region has approximately 7,000 people registered as having a profound disability. A meeting is planned with the local MPs prior to the election to have our needs heard, and be informed about our voting choice. Members were excited about the possibility of a bike ride to be organised to raise awareness of people with a spinal cord injury. A BBQ and other activities are planned after the ride. Contact me if you are able to help with this event. Members shared information on the local Toowoomba Advocacy and Support Centre. The lunch time meeting proved successful and we are encouraged by new attendees and the enthusiasm at our first meeting. We are off to a great year!

**Back row L to R: Dr Margaret Peel, James and Anita Yonkers, Dorothy Harrison. John and Leigh Schoots, Ann Pointon. Front Kaye and Clive Bush.**

# Association assists Logan police district in a **SNAPP**

Megan Illmer, Communications Coordinator



Attending the SNAPP launch were (from left) Acting Assistant Commissioner South Eastern Region Stephen Hollands APM, Logan District Police Project Manager Avril Davis, Spinal Injuries Association CEO Mark Henley, Constable Nina Sheehan, Spinal Injuries Association Client Services Manager Frances Porter and Inspector Garry Watts.

Two Spinal Injuries Association executive managers will be part of a reference group that assists in the implementation of the Queensland Police Service (QPS) Disability Plan in Logan.

Client Services Manager Frances Porter and Community Relations Manager John Mayo will be involved in regular Special Needs Action Plan meetings with Police (SNAPP) Project forums, following

the inaugural group meeting in November 2008. At the launch of SNAPP held at the Beenleigh PCYC in March, SNAPP's aims of incorporating both the Special Needs component of the Operational Procedures Manual and the QPS Disability Action Plan into one initiative, were discussed.

"Our Association's involvement in SNAPP will benefit the needs of our members and other residents with

a physical disability in the Logan region," Frances said.

"It's vital that they have legitimate representation in the QPS Disability Action Plan."

Nineteen Logan police officers have volunteered as Special Needs Liaison Officers to communicate between the QPS, service providers, disability organisations and people with a disability in the region.

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## PARAVILLA ~MACKAY~



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The five bedroom house has been purpose built and is close to shops, doctors surgery, hotels and the base hospital.

For further information phone or fax the co-ordinator on (07) 4957 2180  
E-mail [mdsia@mackay.net.au](mailto:mdsia@mackay.net.au)

# Following a feeling of loss Peter finds himself in Counselling

Reprinted with permission from Fraser Coast Chronicle, 24 December 2008

Four years ago, Peter Kalbfell, 43, admits he felt lost.

Eight years ago Peter became an incomplete quadriplegic after a car accident. He was searching for a way to make a contribution and regain independence after recovering from the crash, so he did a counseling course and took a voluntary position at Maryborough's Lifeline centre. He started helping people who were dealing with some of the same issues he was – loss, pain, anger and grief. He knew he was making a valuable contribution. Twelve months ago he was promoted to the role of supervisor on call at Maryborough's Lifeline office and two months ago he was offered paid employment – he couldn't be happier. Peter is also involved with the Spinal Injuries Association.

"When I first started (at Lifeline) I felt pretty lost," he said.



Lifeline assistant telephone counsellor and trainer Peter Kalbfell, and telephone counselling coordinator Yvonne Scanlon handling an explosion of calls for help.

"I'd had the accident in 2000 and didn't know what I wanted to do or where I wanted to go."

Having led a very active life before the accident, working as a painter in the Northern Territory, the adjustment was difficult. "I have empathy for a lot of the people who call," Peter said. "It helps me to work with them."

Peter is applying to go to university to study for a degree in counseling.

He knows he owes his sense of purpose to his time spent working at

Lifeline. "Confidence was the biggest thing after the accident.

"At Lifeline I get to interact with so many people. Lifeline has given a lot to me and I've given a lot back."

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Chatswood Hills State School students are rewarded for being the school in the Brisbane region with the most number of students to have seen SEAT since the program began. Member for Springwood Barbara Stone (from top left), School Principal Keith Graham, Minister for Disabilities Lindy Nelson-Carr, Spinal Injuries Association CEO Mark Henley and SEAT presenter Wayne Horkings helped them celebrate the occasion; and (from top left) Spinal Injuries Association Ambassador Greg Cornelsen, school principal Chris McMillan and SEAT presenter Robert Spencer with Elanora State School Captains at the launch

# SEAT successfully launches for a busy 2009

Megan Illmer, Communications Officer

Three Queensland schools have been recognised for their dedication to injury prevention as “Schools that Rule”.

Townsville’s Weir State School, Chatswood Hills State School in Brisbane and the Gold Coast’s Elanora State School have all had the most number of students view a SEAT presentation in their regions since the program began 22 years ago.

A presentation was held at each school, with every student receiving a ruler that read: My school rules at

injury prevention. Each of the schools will also receive a free SEAT presentation this year to thank them for their continued support.

To launch SEAT at secondary schools in 2009, almost 3,000 Queensland Year 11 and 12 students will receive free L-plates, thanks to funding from NRMA Insurance’s **communityhelp** Grants.

SEAT presenters throughout the State will distribute the L-plates during presentations in the first semester of the school year.

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# SEAT moves from the classroom to the workplace

Megan Illmer, Communications Officer

While Queensland has the second lowest rate of spinal cord injuries in the country in general, in regards to workplace accidents, the Sunshine State still has the second highest incidence of this type of injury. To combat this, the Association's Spinal Education Awareness Team (SEAT) is now venturing into the workplace.

SEAT at WORK is being launched this year, with SEAT presenter Robert Spencer already speaking to 100 Watpac construction workers and 350 Energex third-year apprentices.

The Australian Technical College, which is a senior school for students combining study with apprenticeships and traineeships, has also hosted a SEAT at WORK presentation for 200 students.

"When I sustained my injury, I was 18-years-old and a third year-apprentice," Robert said.

"By sharing my story of how much my life changed because of my accident, I want these workers to realise safety at work isn't something to be taken lightly."



SEAT at WORK presenter Robert Spencer shares his experience with third year Energex apprentices.

SEAT at WORK also offers presentations that are more focused on disability awareness and showcasing how best to communicate with someone who has a disability to ensure they remain a valued customer or client.

For more information on SEAT at WORK, phone Fundraising and Communications Manager Carol Haffke on 3391 2044.



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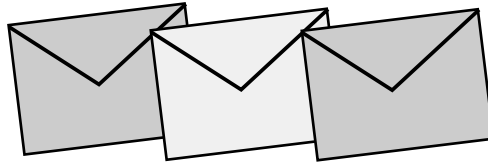
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# Mailbag



## Transport practices

I note that on page 3 of the current edition of "Imprint", the management committee expresses its formal opposition to several transport practices, including the following: "trains using ramps and staff manually embarking and disembarking passengers who use wheelchairs." As someone in a wheelchair who uses the Brisbane suburban rail network regularly, I find this curious and needing explanation.

Given the differing heights of train carriages and station platforms throughout the network, how else are wheelchair passengers to access the trains if ramps are not used? The current system of portable ramps on trains used by QR works reasonably well and, so far as I can see, it is reasonably safe and effective. If the management committee has an alternative viable scheme in mind, it should explain this rather than just criticising the current procedures.

As for the manual embarking and disembarking of people who use wheelchairs by QR staff, I have seen very little of this in my years of using the system. Most

people in wheelchairs who use trains use motorised chairs or buggies which need no manual assistance. Those in manual chairs usually push themselves or have carers/friends who do it for them. I have seldom seen QR staff perform this task. They usually confine themselves to deploying the ramps.

My concern is that if QR thinks the management committee's view is shared by most people who use wheelchairs (arguably not the case), then QR may withdraw the service or modify it in ways which do not suit the wheelchair community. I, along with many other members of the now-defunct Transport Lobby Group, worked hard in the 1990s to help bring about a wheelchair-friendly rail network. Many of us would be saddened and infuriated if this work is undone or wound back.

I respectfully request that the management committee publish an explanation of their position, or withdraw their comments.

Yours sincerely  
Christopher Gilbert.

### Editor's note:

*Whilst we appreciate that you may be adequately served in your train travel it is not the case for all members. There are various types of ramps being used by Queensland Rail (QR) across its suburban and regional network. Some can be used independently, others cannot and require manual handling by station staff. Some members are sustaining injury using ramps.*

*Difficulties also arise due to insufficient circulation space for ramps at many stations, that is, insufficient straight line space between the carriage door and the station building. One potential consequence of disembarkation from a carriage downhill on a ramp is the prospect of hitting the station wall. This is untenable.*

*The Association, in developing a Transport position statement, is seeking best practice universal design outcomes that offer safe, accessible travel for all users. Raised platforms matched to the door entry/exit 'accessible' carriages will eliminate steep ramps, manual handling and insufficient circulation space issues. QR is aware of this and has, for example, installed a raised platform at the re-furbished Fortitude Valley Station (photo story in Imprint Nov/Dec issue).*

*There is a new management structure at QR and its Stations Manager has asked the Association to work with his team to remedy the current issues. This process is positive and intended to enhance the pioneering work of the Transport Lobby Group, which, for those who are not aware, comprised a small group of Association members who achieved remarkable results in securing transport services and transport infrastructure.*

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**Quantum Vibe Electric Wheelchair 2004:** Five (5) speeds; back wheel brakes; complete with battery and battery charger. Red and black colour. Good condition. Cost \$6,950 – Sell for **\$3,500** ono. Ph: Norma 3396 2994 Manly.

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## Homes

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